

ICWNA



INTERNATIONAL COMMUNITY OF
WOMEN LIVING WITH HIV
NORTH AMERICA

SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS FOR WOMEN LIVING WITH HIV

The International Community of Women Living with HIV North America (ICW-NA)

ICW-NA Call to Action

ICW-NA advocates for improved access to information about sexual and reproductive health and rights along with more research and implementation of evidence-based programmatic interventions to ensure that women living with HIV in North America receive accessible, culturally appropriate, non-discriminatory care, treatment, and support that takes into account the varied and layered lived experiences of women living with HIV.

ICW-NA is a regional network of ICW Global accountable to its membership of women living with HIV in Canada and the United States. ICW-NA shares the global vision of a world where all women living with HIV live free of gender oppression, realizing and claiming our full rights inclusive of sexual, reproductive, legal, social, economic and health rights. ICW-NA exists to lead efforts to secure and improve the quality of life for women living with HIV in North America. We do this by mobilizing, organizing, advocating, mentoring, and raising consciousness on the issues and policies that directly affect our lives.

This policy brief represents our overview of the current state of the sexual and reproductive health and rights of women living within Canada

and the United States after review of published literature, current statutes, and policies and an unpublished survey of our membership. Issues among women living with HIV in Canada and the United States are similar, although demographics, cultures, structures, and policies differ between the two countries. Our membership survey, conducted in November 2015, confirmed that ICW-NA members consider the sexual and reproductive health and rights of women living with HIV as critical issues in both the United States and Canada. The topics of sexual and reproductive health and rights are very broad. It is not our intention to fully expand on each topic, but rather provide a snapshot of the issues in North America.

Women living with HIV in the United States and Canada

Women living with HIV in the United States and Canada are ethno culturally and socio economically diverse and include women of all ages and lived experiences who are heterosexual, lesbian, bisexual and transgender.

According to the Centers for Disease Control in the United States, approximately one in four of about 1.2 million people

living with HIV are women. Heterosexual contact accounts for 84% of all new transmissions among women. An estimated 88% of all women living with HIV in the United States are diagnosed, leaving 22% who are unaware of their status. Black/African American and Latina women continue to be disproportionately affected by HIV, compared with women

ICW-NA Call to Action

ICW-NA urges the implementation of family planning and sexual health programs for women living with HIV that emphasize the rights of women to make informed choices about their reproductive lives, encourage healthy sexuality.



ICW-NA demands the inclusion of the meaningful involvement of women and girls living with HIV at all levels of policy and program development in areas that affect our reproductive and sexual health and rights.

of other races/ethnicities. Despite living in a resource rich country, only 45% of women living with HIV are engaged in care with 32% having achieved the gold standard of HIV viral suppression.

The Public Health Agency of Canada (2014) reports an estimated 16,880 women living with HIV, accounting for about 22.4% of Canada's total. About 21% of all people living with HIV do not know their status. However, this data is not disaggregated by sex. Women in Canada account for about 23.2% of all new diagnosis including 79.2% reported through heterosexual contact,

and 20.8% attributed to injection drug use. Among new transmissions in Canada, women who identify as black (36%) and those who are First Nations, Inuit, and Metis (31%), are disproportionately affected by the epidemic than other races. More women (8%), than men (5%) in prison are living with HIV. More women living with HIV in Canada report that they are in care than women in the United States. Additionally, 56% of women say they are currently taking prescribed HIV drugs compared to 75% of males in Canada.

Global Sexual and Reproductive Health and Rights for all Women

The World Health Organization defines Reproductive Health as “a state of complete physical, mental and social well-being, and not only the absence of disease” or illness, related to the reproductive system and its functions and sexual health as “the enhancement of life and personal relations, and not only with counseling and care related to reproduction and sexually transmitted diseases.”ⁱⁱ

Reproductive rights include “the rights of couples and individuals to decide freely and responsibly the number and spacing of their children.”(WHO) It also includes the right to have the information, education, and means to reach “the highest standards of sexual and reproductive health, and to make decisions about reproduction free of discrimination, coercion, and violence.”(WHO)

Regarding sexual rights, all women, including women living with HIV, have

the right to decide freely and responsibly all aspects of their sexuality. Sexual rights include women's rights to protect and promote their sexual health and to “be free from discrimination, coercion or violence in their sexual lives” and all sexual decisions. Additionally, women have the right to “expect and demand equality, full consent, mutual respect, and shared responsibility in sexual relationships. Sexual rights include

“...all women, including women living with HIV, have the right to decide freely and responsibly all aspects of their sexuality.”

rights to sexual expression and pleasure”.(WHO)

ICW-NA Call to Action

ICW-NA encourages more research and availability of female-controlled barrier methods and microbicides.



ICW-NA recommends improved screening for cervical cancer among women living with HIV.



ICW-NA supports research, documentation, and litigation around human rights abuses against women living with HIV—for example, forced sterilization or abortion or denial of SRHR services;

Sexual and Reproductive Health and Rights for Women Living with HIV in North America

Advances in HIV treatment have had a significant impact on mortality and transmission (to a child or partner) for women living with HIV in North America.ⁱⁱⁱ A woman diagnosed with HIV today can expect to live close to normal life expectancy.^{iv} This new era of life with HIV is very different from the death sentence first imposed by such a diagnosis. HIV treatment has dramatically reduced the risk of HIV transmission during pregnancy (vertical transmission) to less than 1%,^v and the likelihood of transmission to a sexual partner reduced by as much as 96%^{vi}. Considering the relatively new prospect of living well with HIV, women and girls are attempting to live their lives to the fullest including finding and maintaining satisfying relationships and fulfilling reproductive and sexual desires and intentions.^{vii} Despite tremendous gains in medical research and interventions, women living with HIV in North America continue to face social and structural obstacles to achieving sexual and reproductive health and rights. The barriers are many and complex including gender inequities, healthcare provider and policymaker bias and HIV stigma which is compounded by racism, classism, immigration status, stigma towards women who use drugs or alcohol and women who have experienced violence, incarceration, and sex work.^{viii}

For women living with HIV, their rights to reproductive and sexual health as described by WHO, are undermined by stigma leading to discriminatory and uninformed policies and practices throughout North America.^{ix} These

practices aim to limit, constrain, or criminalize sexual and reproductive choices for women living with HIV including denial of fertility services, lack support for pregnancy and criminalization of sexual activity. Further, there is limited literature regarding non-biomedical factors related to well-being. Positive Women's Network USA identifies a lack of research in areas such as self-perception, body image, and self-esteem; disclosure; sexual and emotional satisfaction in relationships.^x Failure to address these issues through research and integrated programming is in itself an infringement on the rights of women living with HIV to achieve optimal sexual and reproductive health. Issues related to fertility desires and decisions along with biomedical interventions such as Issues of reproductive health, vertical and horizontal transmission, and gynecological care including contraceptive choices, have biomedical and clinical solutions, and have received more research attention.

A member survey of more than 120 women living with HIV in the USA was conducted and published by the Positive Women's Network USA in 2013 to determine the Sexual and Reproductive Health and Rights issues most affecting women in the US provides further incite that there is little attention paid to issues of well-being and complete health. A smaller, unpublished poll of 22 ICW-NA members indicated that women need more information about their sexual and reproductive health and rights as well as information about recourse for rights violations.^{xi}

ICW-NA Call to Action

ICW-NA supports community-based awareness campaigns to address gender inequalities and promote a woman's right to control what happens to her body and to enjoy satisfying sexual relationships, or to choose not to have sex.



ICW-NA supports all efforts to repeal laws that criminalize the non-disclosure of HIV.

Access to Sexual and Reproductive Health Care and Information

In the North American context, at first glance it would seem that all women have access to basic sexual and reproductive health care. Both Canada and the United States have high levels of expertise in sexual and reproductive health including HIV. North America also boasts some of the most modern medical centers and programming for women's health in the world. Despite the advantage of living in countries that are considered wealthy and well serviced by global standards, women living with HIV continue to experience obstacles in achieving optimal sexual and reproductive health. Barriers to accessing available services include refusal of service by health care providers, geographic distance from healthcare centers, lack of insurance, limited or unavailable

transportation, immigration status and gender inequities including abusive relationships which limit a woman's ability to exert her rights to access health care.^{xii}

Women and girls who identify as lesbian, bisexual, or transgender are further stigmatized by heterosexism, homophobia, and transphobia. Many lesbian and bisexual women do not receive appropriate prevention information, care, or support because care providers do not consider them to be at risk. However, activities such as sex with men, sex trade work and injection drug use remain risk factors for lesbian and bisexual women.^{xiii} Women who identify as transgender often do not receive appropriate care due to lack of knowledge and transphobia by health care providers.^{xiv}

Cervical Cancer Screening

In Canada and the United States most women, about 85% receive regular Pap tests to screen for cervical cancer. However when considering women living with HIV are more likely than other women to acquire HPV and cervical dysplasia greater efforts are required to ensure women receive screening services.^{xv, xvi} Reduced access to existing healthcare settings often results in failure to obtain necessary information and screening for cervical cancer and sexually transmitted diseases as well as female-controlled tools for prevention of

HIV transmission, unintended pregnancy, and safe conception. Additionally, for some populations of women including First Nations, Inuit and Metis women in Canada, and immigrant women in Canada and the United States, access to biomedical interventions and information is not culturally appropriate or universal. Women in remote communities must endure extreme hardship including travel and removal from their communities and traditional customs to access appropriate care.^{xvii}

ICW-NA Call to Action

ICW-NA supports the efforts of its sister community-based organizations in Canada and the United States to improve the sexual and reproductive health of women living with HIV and to regain our right to healthy, satisfying sex lives.

Sexual Activity and Sexual Satisfaction

The World Health Organization recognizes healthy sexual activity and satisfaction as essential rights of all women. However, often women living with HIV are not sexually active or satisfied. There is very little research in this area, but what we do know that

only about half of women living with HIV are sexually active. For women who are dissatisfied with their sex lives, HIV stigma, the threat of criminalization and challenges for disclosure and negotiating healthy sexual activity appear to be to blame.^{xviiiix}

Pregnancy Planning and Pregnancy

Until recently, the fertility desires of women living with HIV to have children are often absent in policy and guideline documents in Canada and the United States. Canada has produced standalone clinical practice guidelines for pregnancy planning in the context of HIV.^{xx} These guidelines serve to assist health care providers and women living with HIV plan safe and healthy

violations. Unique to these guidelines is the community based approach used to develop them. This multi-stakeholder approach to policy development is encouraged by ICW-NA to ensure relevance of the guidance documents and policies.^{xxi} Since the Canadian guidelines were published in 2011, the US has developed similar guidelines for pregnancy planning which emphasize the importance of discussing family planning with all people living with HIV.

“...multi-stakeholder approach to policy development is encouraged by ICW-NA...”

pregnancies. Until guidelines were developed and released, women living with HIV in Canada often faced refusal of services, discouragement from pregnancy and other human rights

Despite the existence of guidelines for pregnancy and pregnancy planning, two babies have been born with HIV in Saskatchewan Canada in 2015, and a third is under investigation.^{xxii} In Saskatchewan, the concentrated, escalating epidemic is exacerbated by multiple forms of stigma and inequitable access to health care by First Nations, Inuit and Metis women. Clearly, this is an indication that more effort is needed to reduce new transmissions during pregnancy and improve access to sexual and reproductive health services and information.^{xxiii}

ICW-NA Call to Action

ICW-NA encourages the use of “people first” language and use of less stigmatizing language when discussing HIV and AIDS issues.

Abortion and Sterilization

Access to unforced, legal and safe abortion and sterilization, free of coercion, are issues of importance to all women. However, studies in both Canada and the United States have shown that women living with HIV are more likely to have unintended pregnancies than other women, increasing the importance of access to legal and safe abortion.^{xxiv} Women living with HIV are also more likely to be sterilized. On a positive note, unintended pregnancies, abortions, and sterilizations among women living with HIV have declined since the availability of antiretroviral HIV treatment.^{xxv} While research shows that women chose to be sterilized and terminate pregnancies more frequently before the advent of effective HIV treatment, what is not clear is the influence of provider bias and level of coercion that existed at the time or today.^{xxvi}

Access to abortion varies both between and within Canada and the United States. In Canada, abortion has been legally unrestricted in since 1988. Under the Canada Health Act, abortion is defined as a medically necessary procedure. Provincial health care, regardless of where a woman lives, or whether she receives an abortion in a clinic or a hospital. However, each province has specific regulations regarding the timing of abortions and where they can be performed (clinics or hospitals). For women living in rural communities, appropriate abortion services may not be available in their communities. Women must travel great distances to receive care which

can be a financial, emotional, and physical burden.^{xxvii}

In the United States, abortion is a politically charged issue. Although the landmark Roe v Wade case granted access to abortion by the Supreme Court, States are responsible for

“ICW-NA seeks to ensure the meaningful involvement of women living with HIV in the development of policies and programs designed to serve them.”

administering health care and have greatly restricted women’s access to legal abortion. Restrictions are on the increase with more than 280 on the books with multiple constraints in some states. Restrictions range from waiting periods, circumstances of impregnation to medical necessity and restricting access to facilities to abortion providers.^{xxviii} Currently, 14 states require a waiting period that requires women to make two trips to the abortion site. For many, as with Canadian women, the additional burden of travel can limit access to services. Lobbying is ongoing to ensure better access to abortion for all women.^{xxix}

ICW-NA Call to Action

ICW-NA seeks to ensure the meaningful involvement of women living with HIV in the development of policies and programs designed to serve them.

Current Response

For Women living with HIV in Canada and the United States progress has been made towards achieving sexual and reproductive health in the biomedical context. Advances in treatment have allowed women to have healthy pregnancies with less than 1% chance of transmission of HIV to the fetus. These same treatment advances have also improved the outlook for sexual health with the introduction of treatment as prevention and pre-exposure prophylaxis (*PreP*). However, most interventions are public health focused aiming to reduce both vertical and horizontal transmission with little consideration for other aspects

of well-being such as enhancement of life and personal relationships and complete physical and mental health. Women-centered research through the Canadian HIV Women's Sexual And Reproductive Health Cohort Study (**CHWOS**) project^{xxx} and the United States The Women's Interagency HIV Study (**WIHS**) have provided a good starting place to gather further data which is relevant to improving the sexual and reproductive health and rights of women living with HIV.

ICW-NA seeks to ensure the meaningful involvement of women living with HIV in the development of policies and programs designed to serve them.

References

- i** ICW-NA Draft Strategic Plan to 2019
- ii** <http://www.cdc.gov/hiv/group/gender/women/index.html> last accessed December 31, 2015
- iii** <http://healthycanadians.gc.ca/publications/diseases-conditions-maladies-affections/hiv-aids-estimates-2014-vih-sida-estimations/index-eng.php> last accessed December 31, 2015
- iv** Public Health Agency of Canada. HIV/AIDS Epi Updates: National HIV Prevalence and Incidence Estimates for 2011. Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada, 2014. <http://www.phac-aspc.gc.ca/aids-sida/publication/epi/2010/1-eng.php#a0505> last accessed December 31, 2015
- v** PHAC data via catie fact sheet available at <http://www.catie.ca/fact-sheets/epidemiology/epidemiology-hiv-women> last accessed December 31, 2015
- vi** I-track data via catie fact sheet available at <http://www.catie.ca/fact-sheets/epidemiology/epidemiology-hiv-women> last accessed December 31, 2015
- vii** World Health Assembly. Women and health: 20 years of the Beijing Declaration and Platform for Action. A68/16 [Internet]. 2015 [cited 2015 Oct 10]. Available from http://apps.who.int/gb/ebwha/pdf_files/WHA68/A68_16-en.pdf last accessed December 31, 2015
- viii** Khosla R, Van Belle N, Temmerman M. Advancing the sexual and reproductive health and human rights of women living with HIV: a review of UN, regional and national human rights norms and standards. *J Int AIDS Soc.* 2015;18(Suppl 5):20280, doi: <http://dx.doi.org/10.7448/IAS.18.6.20280> last accessed December 31, 2015
- ix** Forbes JC, Alimenti AM, Singer J, et al. 21-year review of vertical HIV transmission in Canada (1990 to 2010). *AIDS.* 2012; in press.
- x** Samji H, Cescon A, Hogg RS, et al. Closing the Gap: Increases in life expectancy among treated HIV-positive individuals in the United States and Canada. *PLoS One.* 2013 Dec 18;8(12):e81355.
- xi** Townsend CL, Cortina-Borja M, Peckham CS, de Ruiter A, Lyall H, Tookey, PA. Low rates of mother-to-child transmission of HIV following effective pregnancy interventions in the United Kingdom and Ireland, 2000–2006. *AIDS* 2008;22(8):973-81.
- xii** http://www.hptn.org/web%20documents/HPTN052/HPTN%20Factsheet_InitiationART4Prevention.pdf
- xiii** Chen JL, Phillips KA, Kanouse DE, et al. Fertility desires and intentions of HIV-positive men and women. *Family Planning Perspectives.* 2001;33(4):144-152 & 165.
- xiv** Chandra-Mouli V, Armstrong A, Amin A, Ferguson J. A pressing need to respond to the needs and sexual and reproductive health problems of adolescent girls living with HIV in low and middle-income countries. *J Int AIDS Soc.* 2015;18(Suppl 5):20297, doi: <http://dx.doi.org/10.7448/IAS.18.6.20297> last accessed December 31, 2015
- xv** https://www.unfpa.org/sites/default/files/pub-pdf/SRH_Framework.pdf last accessed December 31, 2015
- xvi** Kumar S, Gruskin S, Khosla R, Narasimhan M. Human rights and the sexual and reproductive health of women living with HIV – a literature review. *J Int AIDS Soc.* 2015;18(Suppl 5):20290, doi: <http://dx.doi.org/10.7448/IAS.18.6.20290> last accessed December 31, 2015
- xvii** UNSPOKEN: Sexuality, Romance, and Reproductive Freedom for Women Living with HIV in the United States, Positive Women’s Network – USA (PWN-USA) publication. November 2013. Available at www.pwn-usa.org. Last accessed December 31, 2015
- xviii** Addressing gender inequalities to improve the sexual and reproductive health and wellbeing of women living with HIV Amin A. *Journal of the International AIDS Society* 2015, 18(Suppl 5):20302 <http://www.jiasociety.org/index.php/jias/article/view/20302> | <http://dx.doi.org/10.7448/IAS.18.6.20302> last accessed December 31, 2015
- xix** Logie, Carmen H et al. “‘We Don’t Exist’: A Qualitative Study of Marginalization Experienced by HIV-Positive Lesbian, Bisexual, Queer and Transgender Women in Toronto, Canada.” *Journal of the International AIDS Society* 15.2 (2012): 10.7448/IAS.15.2.17392. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3494165/> last accessed January 31, 2016

- xx** Marrazzo JM. Sexually transmitted infections in women who have sex with women: who cares? *Sex Transm Infect.* 2000;76:330–2. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1744206/pdf/v076p00330.pdf> last accessed January 31, 2016
- xxi** Keller, et al. Risk of Cervical Precancer and Cancer Among HIV-Infected Women With Normal Cervical Cytology and No Evidence of Oncogenic HPV Infection. *JAMA* 2012;308(4):362-369. last accessed December 31, 2015
- xxii** <http://cid.oxfordjournals.org/content/45/4/510.full.pdf> last accessed December 31, 2015
- xxiii** <http://sogc.org/guidelines/sexual-and-reproductive-health-rights-and-realities-and-access-to-services-for-first-nations-inuit-and-metis-in-canada-policy-statement/> last accessed December 31, 2015
- xxiv** Kaida A, Carter A, de Pokomandy A, Patterson S, Proulx-Boucher K, Nohpal A, et al. Sexual inactivity and sexual satisfaction among women living with HIV in Canada in the context of growing social, legal and public health surveillance. *J Int AIDS Soc.* 2015;18(Suppl 5):20284, doi: <http://dx.doi.org/10.7448/IAS.18.6.20284> last accessed December 31, 2015
- xxv** Sexual inactivity and sexual satisfaction among women living with HIV in Canada in the context of growing social, legal and public health surveillance. Kaida A et al. *Journal of the International AIDS Society* 2015, 18(Suppl 5):20284. <http://www.jiasociety.org/index.php/jias/article/view/20284> | <http://dx.doi.org/10.7448/IAS.18.6.20284> last accessed December 31, 2015
- xxvi** UNSPOKEN: Sexuality, Romance, and Reproductive Freedom for Women Living with HIV in the United States, Positive Women’s Network – USA (PWN-USA) publication. November 2013. Available at www.pwn-usa.org. Last accessed December 31, 2015
- xxvii** 100 Bova C, Durante, A. Sexual Functioning among HIV-infected women. *AIDS Patient Care and STDs.* 2003 February;17(2): 75-83. last accessed December 31, 2015
- xxviii** CHPPG- <http://sogc.org/guidelines/canadian-hiv-pregnancy-planning-guidelines-2/> last accessed December 31, 2015
- xxix** GIPA – The Greater Involvement of People Living with HIV/AIDS. The Paris Declaration. Paris AIDS Summit [Internet]. 1994 Dec 1 [cited 2015 Oct 10]. Available from http://data.unaids.org/pub/ExternalDocument/2007/theparisdeclaration_en.pdf last accessed December 31, 2015
- xxx** <http://www.cbc.ca/news/canada/saskatchewan/2-babies-born-with-hiv-saskatchewan-2015-1.3375742> last accessed December 31, 2015
- xxxi** <http://sogc.org/guidelines/sexual-and-reproductive-health-rights-and-realities-and-access-to-services-for-first-nations-inuit-and-metis-in-canada-policy-statement/> last accessed December 31, 2015
- xxxii** Loutfy, M., Raboud, J., Wong, J., Yudin, M., Diong, C., Blitz, S., Margolese, S., Hart, T., Ogilvie, G., Masinde, K., Tharao, W., Linklater, G., Salam, K., Ongoiba, F., Angel, J., Smaill, F., Rachlis, A., Ralph, E., Walmsley, S. and for the Ontario HIV Fertility Research Team (2012), High prevalence of unintended pregnancies in HIV-positive women of reproductive age in Ontario, Canada: a retrospective study. *HIV Medicine*, 13: 107–117. doi: 10.1111/j.1468-1293.2011.00946.x available at <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-1293.2011.00946.x/full> last accessed December 31, 2015
- xxxiii** Stuart GS, Castano PM, Sheffield JS, et al. Postpartum sterilization choices made by HIV-infected women. *Infectious Diseases in Obstetrics and Gynecology.* 2005; 13(4):217-222. last accessed December 31, 2015
- xxxiv** Stephenson JM, Griffioen A. The effect of HIV diagnosis on reproductive experience. Study Group for the Medical Research Council Collaborative Study of Women with HIV. *AIDS.* 1996;10(14):1683-1687. last accessed December 31, 2015
- xxxv** Stuart GS, Castano PM, Sheffield JS, et al. Postpartum sterilization choices made by HIV-infected women. *Infectious Diseases in Obstetrics and Gynecology.* 2005; 13(4):217-222. last accessed December 31, 2015
- xxxvi** <http://www.morgentaler25years.ca/the-struggle-for-abortion-rights/access-by-province/> last accessed December 31, 2015
- xxxvii** http://www.guttmacher.org/media/inthenews/2015/07/01/index.html?gclid=CJe_qPTatsoCFY06gQodxJECOA last accessed December 31, 2015
- xxxviii** http://www.guttmacher.org/media/inthenews/2015/07/01/index.html?gclid=CJe_qPTatsoCFY06gQodxJECOA last accessed December 31, 2015
- xxxix** <http://www.chiwos.ca/> last accessed December 31, 2015